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How Can Home Care Patients and Their Caregivers Better Manage Fall Risks by Leveraging Information Technology?

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Abstract

Objectives: From the perspectives of home care patients and caregivers, this study aimed to (a) identify the challenges for better fall-risk management during home care episodes and (b) explore the opportunities for them to leverage health information technology (IT) solutions to improve fall-risk management during home care episodes. **Methods:** Twelve in-depth semistructured interviews with the patients and caregivers were conducted within a descriptive single case study design in 1 home health agency (HHA) in the mid-Atlantic region of the United States. **Results:** Patients and caregivers faced challenges to manage fall risks such as unmanaged expectations, deteriorating cognitive abilities, and poor care coordination between the HHA and physician practices. Opportunities to leverage health IT solutions included patient portals, telehealth, and medication reminder apps on smartphones. **Conclusion:** Effectively leveraging health IT could further empower patients and caregivers to reduce fall risks by acquiring the necessary information and following clinical advice and recommendations. The HHAs could improve the quality of care by adopting IT solutions that show more promise of improving the experiences of patients and caregivers in fall-risk management.

Keywords

fall-risk management, home health care, informatics, health information technology, patient engagement

Introduction

In the United States, home health care, or *home care*, refers to the episodic and intermittent secondary care services provided to home-bound patients in their homes (1). Home health agencies (HHAs) provide home care services under the supervision of a physician through nurses, physical therapists, occupational therapists, speech therapists, social workers, and home aides (2). By receiving home care, patients can gain strength, recover, and become independent more quickly (3,4). Home care can also benefit the health-care system by reducing the expensive hospital readmissions and emergency department (ED) visits (5,6). Since HHAs mostly serve the elderly (7), an increasing population in the United States (8,9), the utilization of home care services is rising and it is expected to increase in the near future (10).

During home care episodes, falls become a major concern for patients who are often vulnerable and frail (11). Falls can easily lead to injuries, major health problems, and death (12). Currently, “emergency care for injuries caused by a fall” ranks as the top potentially avoidable event in home care (13). Furthermore, falls negatively impact the utilization

outcome measures of HHAs (14) and increase health-care costs (15) by increasing the ED visit (16) and hospital readmission rates (17). In 2013, the direct medical costs for falls reached nearly US\$34 billion, with an average hospital cost for a fall injury being nearly US\$35 000 (18). Therefore, effective *fall-risk management*, which involves performing assessments and taking the necessary interventions that target the reduction of falls (19,20), becomes an important priority for home care to fulfill its promises.

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Table 1. Study Participants' Profiles.^a

Role	Age	Gender	Employment	Education	Ethnicity
Patients (7)	18-30 years (3)	Female (7)	Retired (7)	High school (1)	African American (2)
Caregivers (5)	31-64 years (4)	Male (5)	Employed (4)	College/bachelors (8)	Asian (2)
	>65 years (5)		Unemployed (1)	Graduate (3)	Hispanic/Latino (2)
					Caucasian (6)

^aNumbers represent the counts in the sample.

However, fall-risk management during home care episodes is highly complex and challenging. Home care patients are not constantly monitored by clinicians (21) and are prone to misunderstand, forget, or ignore health-care advice (22). Fall-risk management must involve both patients and their caregivers (23) because patients may have diminished abilities to perform the activities of daily living such as walking and impaired cognitive abilities due to Alzheimer disease or dementia (24).

Information technology (IT) can potentially play an enabler role when it comes to the delivery of timely, relevant, and useful information that improves the quality of care and health outcomes while reducing the health-care costs (25). Although health IT was shown to have a positive impact on patient experience in care in certain instances (26,27), there has been no evidence at the time of this study about how patients and caregivers can leverage health IT effectively for better management of fall risks while receiving home care services. To address this gap, this study first identified the challenges of patients and their caregivers in fall-risk management during home care episodes. Then, it explored the opportunities to leverage health IT solutions to improve their experiences with managing fall risks at home.

Building evidence about the experiences of patients and caregivers with managing fall risks can support the clinicians to improve fall-risk management by increasing engagement (28,29) and improve the quality of care (30). Furthermore, such evidence can play a crucial role in helping HHAs understand how health IT can be leveraged more effectively to improve their performance and increase patient satisfaction. For this purpose, examining the needs, preferences, and day-to-day challenges of patients and their caregivers in fall-risk management becomes a prerequisite (31).

Methods

Approach

A qualitative approach (32,33) was followed to collect rich and detailed information. This approach was appropriate for examining the experiences of patients and their caregivers (34). This research was a part of a descriptive single case study (35) in one HHA in the mid-Atlantic region of the United States. A case study was appropriate because the phenomena of interest were inseparable from their context (35). Using a purposive sampling strategy (36), seven high-fall-risk patients and five caregivers of at-risk patients were

recruited by the HHA (see Table 1). Prior to data collection, the institutional review board approval was obtained.

Interviews

Twelve semistructured interviews were conducted with patients and caregivers to gain in-depth information about the research topics (37). The interviews helped elicit detailed information that could not have been found by other methods such as surveys (38). Each interview involved one participant and lasted approximately one hour. The interviews were conducted over the phone, audio recorded, and transcribed verbatim by the researchers. The protocol for the semistructured interviews was patient-centered and designed based on a number of well-established qualitative methods for eliciting patients' experiences (39). The participants were asked to discuss the challenges and opportunities associated with fall-risk management during the home care episode. Additionally, the participants were asked about the opportunities for leveraging health IT solutions that are potentially useful to improve fall-risk management during home care episodes. To ensure a common understanding among the participants, the researchers provided definitions of health IT solutions that could potentially assist patients and caregivers to better manage fall risks during the home care episode. Problem analysis (40,41), outcome analysis (42), and technology analysis (43) techniques were used in preparing the interview questions. These techniques are established systems analysis and design techniques geared toward understanding the challenges and opportunities as well as identifying how information systems and technology can be used for improvement.

Analysis

The Framework method (44) was used to analyze the interview transcripts. The analysis was iterative throughout the study (45) and started immediately after the first interview. The researchers followed the steps outlined in Framework, which involved constructing an index, labeling the data according to the index, sorting, summarizing, and synthesizing the data. The researchers met regularly to discuss the findings from each step as well as the concepts and themes that emerged. Data saturation was achieved on the 10th interview; however, the researchers preferred a cautious approach and still completed the remainder of the interviews as scheduled.

Table 2. Selected Representative Quotes From the Interviews.

Q1	"I thought I was in good condition, and when I step inside of my house I said I can make it and that's when I fell." (P-6)
Q2	"I think that he was in denial of his physical limitations." (CG-4)
Q3	"I live alone and do not have anyone sleep here in the home." (P-11)
Q4	"My mother's cognitive abilities are in and out . . . She cannot follow directions." (CG-1)
Q5	"I find myself in the middle, having to tell them a lot of the time what's happening." (P-6)
Q6	"Unfortunately, the coordination of fall services between the agency and doctor's office is terrible I think." (CG-5)
Q7	"The agency has not received an update on blood pressure medications, so I guess they didn't receive one from the primary care doctor and they didn't receive one from me because I didn't think there was any need to let them know, and they didn't ask for an update. So, I guess there is a disconnect." (CG-7)
Q8	"When you start dealing with a population in their 70s and early 80s, you really need to start considering a system that is designed so a family member is a point of contact. Letting them access that site, those notes, 'this is what we discussed with the patient and with the family member, this is what our goal is, this is what we want to achieve.'" (CG-4)
Q9	"They told me 'be careful when you get up from lying down, your blood pressure may change' to the change in, I won't say altitude, but position." (P-2)
Q10	"They explained all the medications, their side effects on balance, and everything." (P-3)
Q11	"They taught him proper ways of getting in and out of bed and transferring from bed to wheelchair." (CG-4)
Q12	"I think you can always get more information about which DME to select or other peoples' experiences and new developments. That would be very helpful I think." (P-8)
Q13	"When my father was discharged from the hospital, they advised us to purchase a walker because his insurance did not cover it. I had no idea that there are many options for walkers. It was overwhelming when I tried finding one that would work for him, but the PT was very helpful in finding one." (CG-12)
Q14	"Telehealth would be great for my mother. Maybe she can ask quick questions about her meds and balance." (CG-7)
Q15	"I have my son who has helped me look up certain things like Guillain-Barre syndrome and things like that." (P-10)
Q16	"Usually on the Internet, there is too much info. You don't know who is right and who is wrong, so I don't trust it." (P-10)
Q17	"I'll save some e-mail I get on COPD [chronic obstructive pulmonary disease] . . . I learned to be careful and not to get my feet snarled up in the cord from portable oxygen device or I would go down." (P-9)
Q18	"Because physically you can't be there for every visit, it would great to get a summary from the clinician, so you're updated on what's going on." (CG-7)
Q19	"Videos that would help the patient and the family member show them that they're not the only ones who go through this, and these are the problems and this is what they can do." (CG-4)
Q20	"She has three medication times, so she hears it, she knows that she needs to do that now." (CG-1)
Q21	"If you have a program that actually speaks to them on their programming, that reminder them to take their medications or do the exercises." (CG-1)
Q22	"We have the Wii. The sports programming. I tried to get her into bowling and tennis and that has worked. My mother is more fit now than she's been in several years." (CG-1)
Q23	"My father has this necklace with a button on it. If he falls, he can press it and it will call the fire department to come and assist him or take him to the hospital." (CG-12)
Q24	"He has a . . . what do you call them? Fitbit? that keeps track of how active he was." (CG-5)
Q25	"It's being able to afford those things, depending on how expensive they are, that would be the problem." (CG-7)
Q26	"I don't like technology. Call me paranoid, but I worry that my information will get stolen." (P-11)
Q27	"Like anything that's unknown and new, got to put it out there through your groups and get your feedback." (P-8)
Q28	"My youngest son's girlfriend is very familiar with all this stuff . . . She's a very smart gal, and I'm very interested in what she has told me about the system." (P-9)
Q29	"Why should I need it to count how many step I walk? How far I walk or how many calories I burn today. I don't need to know that. I'm not a health conscious person. I don't need to know about the heartbeat and everything." (P-10)
Q30	"[Referring to IT] because it's complicated . . . I just have a hard time grasping the concept of all that stuff." (P-9)
Q31	"Using health IT depends. My mother has dementia." (CG-1)

Abbreviations: CG, caregiver; DME, durable medical equipment; IT, information technology; PT, Physical Therapy; P, patient; Q, quote.

Results

Challenges in Fall-Risk Management

Psychological challenges. The patients and their caregivers expressed various challenges for better fall-risk management. The patients' expectations sometimes did not match the reality of their ambulatory status: One patient reported that she fell after returning home from rehab when she thought she was able to perform the daily activities she used to perform (see Q1 in Table 2). One caregiver noted that

denial of the inability to ambulate free of assistance is what had her father-in-law fall several times (Q2). Another challenge was that some patients did not have adequate family support at home: One patient lived alone and only had help during the day (Q3). For some elderly patients, their cognitive abilities to follow clinical advice were hindered (Q4).

Communication and coordination issues. Patients and caregivers often were the middle person having to communicate the relevant information for fall-risk management between the

HHA and the physicians (Q5). Three caregivers mentioned that there was a lack of coordination between the HHA and the physicians about fall risk interventions (Q6). Those caregivers assumed the communication was well established between the HHA and the primary care physician; therefore, they did not see the importance of communicating critical information relevant to fall-risk management such as changes in patients' medications that affected balance (Q7). Two caregivers stressed that family members should have been more adequately informed and involved in the management of fall risks by knowing the patient's physical therapy progress and what exercises could be performed safely (Q8).

Information needs. The patients and their caregivers indicated that the clinicians provided them with basic information about fall-risk management. The clinicians instructed the patients and their caregivers to take precautions such as monitoring their blood pressure regularly, especially when moving (Q9). Additionally, the patients learned about medications and their effects on fall risks (Q10); they also learned how to transfer from the bed to the wheelchair (Q11). One patient was interested in learning how other patients selected the durable medical equipment (DME) and arranged the home environment to become safer (Q12). Three caregivers said that it was difficult to identify and purchase the appropriate DME such as wheelchairs or walkers, without expert clinical advice (Q13).

Leveraging Health IT for Fall-Risk Management

Delivering information. Although none of the participants used telehealth solutions, seven participants expressed that its use could be beneficial when they needed to ask the clinicians quick questions about DME selection or the effects of a newly prescribed medication on balance (Q14). With only one exception, all of the participants reported having a computer with access to the Internet. One patient reported using the Internet to find more information about his condition and how it affected his fall risks (Q15). However, the same patient carefully evaluated the trustworthiness of online information because he did not trust much of the online content (Q16). Another patient said that he was subscribed to an e-mail list that shared information about chronic obstructive pulmonary disease, some of which he thought was related to reducing his fall risks: for example, ideas for managing the oxygen delivery cords from portable oxygen equipment to reduce tripping hazards while walking (Q17).

Increasing awareness and adherence. One caregiver said that patient portals could be beneficial to keep her informed of the patient's progress because she was not able to be at home for all the visits (Q18). Another caregiver said that patient portals could provide a forum for moral support and make online educational material on fall-risk management available and accessible (Q19). Three participants used

smartphones to increase adherence to clinical directions: For example, one caregiver purchased a smartphone for her 80-year-old mother and used the alarm functionality to remind her mother to take her medications on time to avoid going into a hypotensive state (Q20). The same caregiver also said that it would be useful to use apps on smart televisions to remind her mother to take her medications or perform physical therapy exercises aimed at reducing fall risks because her mother was in front of the television constantly (Q21). One caregiver reported using video game consoles such as the Wii Fit with her mother to improve overall fitness and reduce fall risks by performing exercises while playing (Q22).

Enabling monitoring. None of the participants' homes were equipped with sensors that were capable of detecting falls. However, two patients subscribed to a fall alert system that notified local emergency services by pushing a button after a fall (Q23). One caregiver used a wearable fitness tracker to keep track of the patient's daily routines and detect abnormal patterns in the activities of daily living such as dimensioning number of steps, which could indicate an increase in fall risks (Q24).

Barriers to adoption. When asked about the barriers to adopt health IT solutions for fall-risk management, the participants mentioned that high costs prohibited their ability to purchase some IT solutions (Q25). Only one patient said that he was concerned that his privacy was going to be invaded if he started using IT (Q26). One patient resisted any new IT solution and often wanted to see what others thought of it first (Q27). Another patient said that he needed others' advice about using a particular health IT solution before actually using it (Q28). One patient did not see the benefits of health IT and how it could help with reducing falls; he was not interested in keeping track of his step count or caloric intake (Q29). One patient said that he did not use health IT solutions because they were complex and he did not understand how to use them (Q30). One caregiver mentioned that one central reason why patients did not use health IT solutions was due to the patients' diminishing cognitive abilities (Q31).

Typologies

Based on the researchers' higher level interpretations of the results, five typologies of the participants emerged as depicted in Figure 1. These typologies were about the participants' knowledge, need for information, perceptions, engagement, and technology adoption levels in fall-risk management.

Fall risk knowledge. Six participants reported having only basic understanding of fall-risk management; these participants did not have enough information about the medication effects on balance or how to organize and modify the

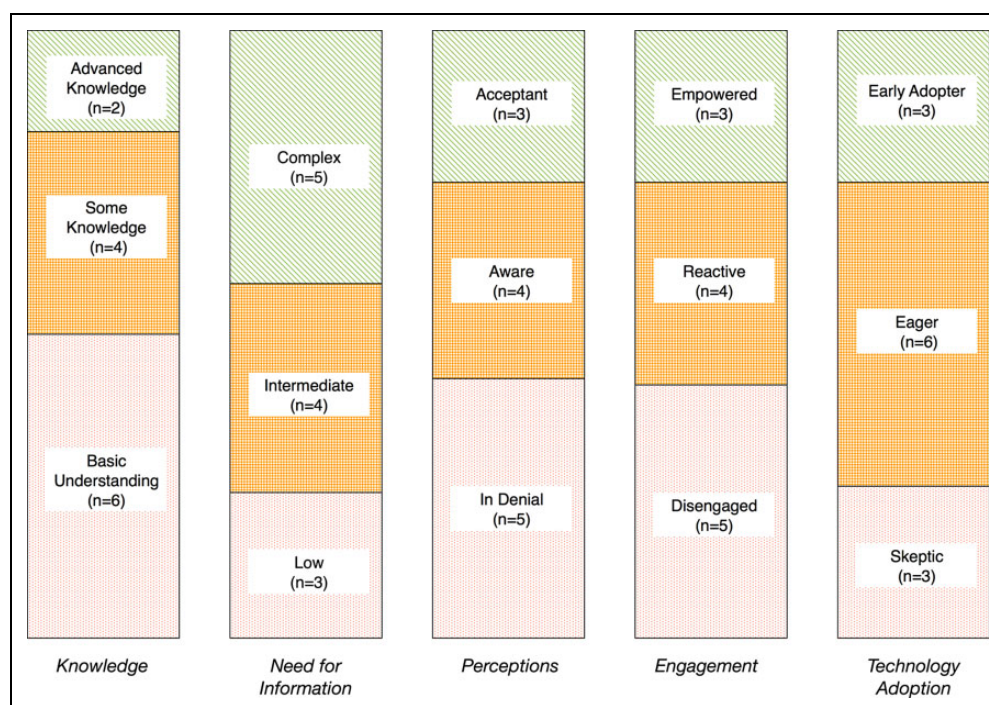


Figure 1. Participant typologies emerging from the data.

home environment to reduce fall risks. Four participants reported having some knowledge on how to mitigate fall risks and understood how the health conditions affected these risks. Only two participants reported having advanced knowledge about fall-risk management due to their professional careers in health care: One was a retired nurse and the other was a home aide.

Need for information. The results indicated that five participants, who had or dealt with complicated health issues, required more complex information about how to manage these issues while effectively reducing fall risks. Four participants needed intermediate information because they had some knowledge about fall-risk management, while three participants needed less information, in comparison with others, due to their advanced knowledge or less severe health needs.

Perceptions of fall risks. The results indicated that four participants had difficulties coping with the reality of their diminished abilities to manage fall risks—they did not take direct actions to reduce them. For example, one patient did not think she needed assistance when walking despite her weakness. Five participants were aware of the specific fall risks but only managed them occasionally, for example, using the walker only for certain tasks. Three participants were accepting of their limitations and took the necessary steps to reduce fall risks.

Engagement. The participants' perceptions influenced their engagement levels in fall-risk management. Five participants were characterized as disengaged with fall-risk management because they were unaware of interventions and strategies to reduce fall risks and were not even motivated to learn about them. Four participants were reactive to clinical advice and only followed directions after being told by clinicians. Only three participants were empowered to take actions to reduce fall risks and leveraged health IT solutions to assist them. The empowered participants followed directions from clinicians, were interested in continuous learning about fall risk reduction strategies, and wanted to be included in the communications about the patient's progress.

Technology adoption. The results suggest that three participants were skeptical about the IT solutions' ability to reduce fall risks. High costs, privacy concerns, issues with trusting the technology (46), and the lack of knowledge on how to use the health IT solutions were among the barriers that prohibited adoption of IT solutions for fall-risk management. Despite these barriers, six other participants were eager to experiment and explore the use of health IT solutions such as visiting websites with information about how a specific disease affected fall risks or receiving e-mails about fall safety recommendations. Three participants were among the early adopters of health IT solutions to manage fall risks such as using wearable fitness trackers to measure activity levels or video game consoles to promote exercise.

Discussion

The results uncovered different challenges facing the patients and their caregivers in fall-risk management during home care episodes. As reported in the results, various challenges with managing fall risks negatively affected the experiences of patients and their caregivers in managing fall risks. In this study, most participants were either disengaged or reactive in fall-risk management. For fall risk interventions that are supported with health IT solutions to be effective, these solutions should further empower the patients and caregivers to participate actively during the care episode, take actions that reduce fall risks, and maintain healthy behaviors.

Additionally, the results show that there is a considerable room to utilize IT solutions to increase patient and caregiver knowledge and engagement in fall-risk management. Recent studies reported that many patients and caregivers did not have adequate understanding of fall-risk management strategies after they are discharged from the hospital (47), and a high number of patients did not feel competent to manage their medications and health conditions (48). In this study, most of the patients and caregivers showed an interest in leveraging health IT solutions to better manage fall risks. Effectively leveraging health IT could empower patients and caregivers to acquire the necessary information as well as follow clinical advice and recommendations (49,50), which are necessary to achieve better outcomes and reduce fall risks.

Although the results showed that many homes today have access to the Internet and a growing digital infrastructure, it is not entirely correct to assume that health IT will be adopted rapidly by patients and caregivers. Rather, as the technology advances in time, so will the infrastructure to support it in the home (51). Carefully investigating and understanding the barriers to health IT adoption by patients and caregivers becomes important for successful implementation of projects.

The results could also be useful for HHAs to improve their ratings in the Home Health Care Consumer Assessment of Healthcare Providers and Systems (HHCAHPS) survey (52) by understanding the various challenges and opportunities affecting the experiences of patients and their caregivers in fall-risk management. The 2015 HHCAHPS results reported that 16% of patients said that their home care team did not discuss their medications, pain, or home safety with them (53). To improve the experience of patients and caregivers in fall-risk management and score higher on HHCAHPS surveys, HHAs could adopt solutions such as patient portals that could help them improve the communication and reinforce the education of patients and caregivers about fall risks and home safety (54,55), investigate providing the patients and caregivers access to the clinical notes in the electronic health record (56), and examine care coordination problems and enhance information sharing with hospitals and physicians by leveraging health information exchange solutions (57).

Limitations

Although the sample size interviewed was small, the study was purposefully designed to obtain rich and contextual evidence which may not be possible to obtain through nationwide quantitative studies. Future survey studies can collect data from a large number of patients and caregivers across the United States to obtain potentially generalizable results. Because the majority of home care patients are elderly who may have auditory or cognitive impairments, it was not possible to interview some patients. However, their caregivers, who were involved in the care, provided ample information to address the research objectives. The participants in the study may have had access to technology and Internet because they lived in suburban neighborhoods in the mid-Atlantic; this could have not been avoided because the HHA in this case study provided access to these patients. Future research can investigate and compare the needs, challenges, and experiences of patients and caregivers living in rural and nonmetropolitan areas with limited access to technology.

Conclusion

This study examined how home care patients and caregivers can better manage fall risks by uncovering key challenges such as unmanaged expectations, patients' deteriorating cognitive abilities, and poor coordination between the HHA and physician practices. The spread and use of health IT tools to support fall-risk management is limited in home care. The results revealed opportunities for leveraging health IT solutions effectively to further empower patients and caregivers to reduce fall risks by acquiring the necessary information and following clinical advice and recommendations. The evidence uncovered in this study is also useful for HHAs to prioritize their health IT adoption projects and focus on those that show greater potentials to improve the experiences of patients and caregivers in the home setting.

Authors' Note

The study was performed in compliance with the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects and was reviewed by the University of Maryland, Baltimore County's Institutional Review Board.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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